

**TO:** 2gether NHS Foundation Trust Board  
**FROM:** Chief Operating Officer  
**DATE:** 27 November 2009  
**SUBJECT:** Service Experience Report

**PURPOSE**

To provide an overview of patient and public engagement within the Trust for the period July-September 2009

**SUMMARY OF KEY POINTS**

- This report provides evidence of involvement activity within the Trust
- The report includes a summary of service user and carer experience that has been expressed through service user and carer groups/forums, GUIDE & PALS, the voluntary sector and complaints
- The report demonstrates in certain key areas how involvement supports service development and improvement

**RECOMMENDATIONS**

The Board is asked to approve the recommendations within the report:

- to review how the Trust connects with new service users and carers to become involved in the work of the Trust
- to continue to build on the work already undertaken by the service user and carer participation workers by targeting areas of concern in each Strategic Service Unit
- to continue to build on the relationship with LINKs and other voluntary organisations and promote their work within the Trust
- to enhance a co-ordinated approach to service user and carer involvement across all Strategic Service Units to ensure that feedback continues to build on our learning.

**WHICH TRUST KEY STRATEGIC OBJECTIVES DOES THIS PAPER PROGRESS OR CHALLENGE?**

Quality and Safety		Skilled workforce	
Getting the basics right	P	Using better information	
Social inclusion	P	Growth and Financial Efficiency	
Seeking involvement	P	Legislation and Governance	

<b>WHICH TRUST VALUES DOES THIS PAPER PROGRESS OR CHALLENGE?</b>			
Seeing from a service user perspective			
Excelling and improving	P	Inclusive open and honest	P
Responsive		Can do	
Valuing and respectful	P	Efficient	

<b>REVIEWED BY:</b>	
	Date
<b>Forums / Community groups whose views have been sought</b>	
	Date November 2009

## 1. CONTEXT

1.1 The Trust values feedback to enable us, as a learning organisation, to address any areas for improvement and celebrate success. The report contains information relating to the experience of service users and carers across the Trust retrieved from:

- the manager of complaints (Appendix A),
- GUIDE & PALS (Appendix B),
- Older Peoples' services (Appendix C),
- Learning Disability Services (Appendix D),
- The Service User and Carer Participation Workers and the Community Involvement Team Manager.

## 2. AUDIT/REVIEW

The involvement of service users and carers is a central element of health and social care activity and the NHS has duty to consult and involve service users and carers under Section 11 of the Health and Social Care Act 2001 (updated to Section 242 of the National Health Service Act 2006).

## 3. THEMES/CONCERNS

3.1 Areas for improvement identified from user feedback include:

- Improved telephone message response time.  
Action: Strategic Service Units to review their telephone messaging protocols within two months.
- Improved passage of service users between community teams  
Action: Strategic Service Units to establish pathways to ensure a maximum of a seven day process – draft pathway to be available within two months.
- Service users are still enquiring about what is going to happen to day care services with regard to the plans with commissioning.  
Action: Chief Operating Officer to raise with Commissioning Manager at next scheduled meeting.
- Service users with severe eating disorders when discharged from hospital were only receiving two to four counselling sessions compared to eighteen to twenty
- Lack of activities on in-patient wards.

Action: Matron Managers to consider what additional activities would be appropriate.

- Service users from ethnic minority groups felt their dietary needs were not being catered for within the in-patient units.

Action: Matron Managers to ensure that with immediate effect all individual requirements can be catered for by Hotel Services.

- Lack of information relating to those considering a return to work and what is available to them – vocational services now recruited to.

Action: Chief Operating Officer to discuss with PCT further investment in scheme.

- There is a need for better information with regard to Statutory and Non Statutory groups.

Action: User & Carer Participation Team Manager to produce information leaflet detailing the opportunities – draft to be available within two to three months.

### 3.2 Issues highlighted in the attached Appendixes:

- Waiting times for Psychological Therapies.

Action: Service Director for Adults of Working Age to discuss with team and identify process for further reducing waiting times.

## 4. SERVICE USER AND CARER INVOLVEMENT PARTICIPATION SUMMARY

4.1 For the period July – September the User/Carer Participation Team have attended a significant number of meetings/presentations publicising the work of the department and the Trust to gain meaningful feed back and to identify learning as an organisation.

- 56 service user meetings which were attended by 344 service users
- Attended 20 clinical team meetings
- Undertaken approximately 20 presentations covering the trust and its services.
- Provided 10 training sessions for carers
- Attended regular LINKs meetings (both with the staff team at LINKs and the locality meetings with the public
- Assisted with the “moving on” sessions
- Assisted with all of the Making Life Better campaign events

4.2 The Community Involvement Team Manager has met with the following organisations for contract monitoring which includes sessions with service users for feedback on services, these are:

- Independence Trust
- English Church House
- GL Communities
- Scout Enterprises
- Appropriate Adult contract

4.3 The Voluntary Services staff team interviewed a total of 53 potential volunteers during this period and found placements for 37. A total of 42 work experience students worked with us during this period.

## **5 CONCLUSION**

5.1 The trust continues to engage with the community through its User and Carer Participation Team, GUIDE & PALS and the complaints process to build on its learning as an organisation.  
Engagement has also demonstrated the beneficial outcomes of proactively building sustainable relationships and promoting a lessons learnt culture.

**COMPLAINTS REPORT  
JULY – SEPTEMBER 2009**

**1. CONTEXT**

- 1.1 There were sixteen new complaints received during this quarter (July to September) - they are summarised in the first of the following matrices. Any complaints from the previous quarter which were still being investigated at the time of the previous report are summarised in the second of the matrices.

**2. CORRESPONDENCE PERFORMANCE**

- 2.1 On April 1<sup>st</sup> 2009, the Local Authority Social Services and NHS Complaints (England) Regulations came into force. This brought a revised complaints system into effect, merging health care and adult social care complaints.
- 2.2 The new complaints system requires a less process driven method of complaints resolution, especially with respect to rigid time scales and promotes a more flexible approach, emphasising the need for the service user to be involved in negotiating the way in which the complaint is to be handled. A more person centred approach to concerns raised is welcomed by the trust. Complaints received in this quarter have therefore been dealt with in a variety of ways that deliver the best resolution/outcome for the individual and or the carer and not necessarily by a formal investigation and reply from the Chief executive. As a consequence of these changes caution is required with regard to direct comparisons when reviewing time scales.

**Receipt date between  
1<sup>st</sup> July – 31st September 2009**

**Matrix One**

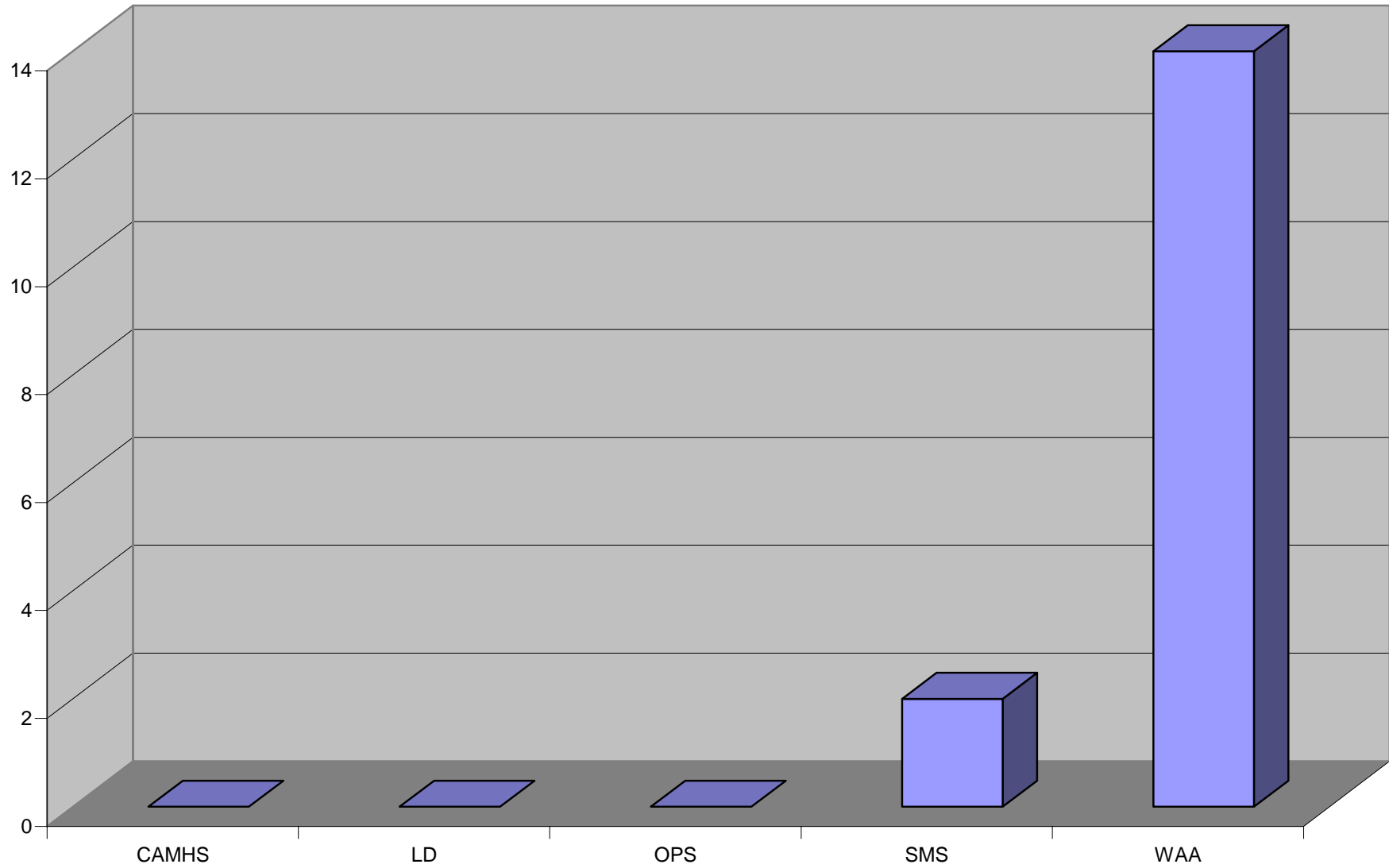
<b>Reference</b>	<b>Response time in working days</b>	<b>Complaint</b>	<b>Action taken</b>	<b>Strategic Service Unit</b>	<b>Service user</b>	<b>Complainant (if different)</b>
C24/10	9	Complaint by carer after poor response to - inability to get through on the phone.	Trust is in process of setting up 0800 no for 3 locality teams which will be diverted to county-wide service during the night time.	WAA		
C25/10		Manner of doctor.	Action taken re manner of Doctor.	WAA		
C26/10	18	Lack of treatment service user received from the Recovery Mental Health Team.	Improve communication and availability of appointments.	WAA		
C27/10	18	Alleged misconnect by member of staff.	Complaint not pursued – opportunity to meet to resolve complaint declined by patient.	WAA		
C28/10	58	Parents of daughter complained that an appointment was unhelpful due to the absence of her records or appropriate clinicians. They reported that their daughter had been promised psychological therapy but that there was now insufficient time for it before she returned to University.	Improved use of electronic records in the future to reduce likelihood of notes going astray. Clinicians to be reminded of issues identified at team meeting.	WAA		
C29/10		No help available for son refusing contact with Trust.	Carer to be contacted and information given concerning help available.	WAA		
C30/10	Ongoing	Nature of communication received from professional staff.	Ongoing efforts being made to resolve issues.	WAA		
C31/10	36	Concerns over a period of time about the continuity of care and information given regarding complainant's sister.	Personal contact made expectations clarified. Personal meeting offered but declined.	WAA		
C32/10	20	Access to Cognitive Behavioural Therapy (CBT)	Acknowledged inappropriate communication with the need for lessons to be learned.	WAA		
C33/10		Service user excluded from service for inappropriate behaviour of selling of drugs.	Complaint not upheld.	SMS		

<b>Reference</b>	<b>Response time in working days</b>	<b>Complaint</b>	<b>Action taken</b>	<b>Strategic Service Unit</b>	<b>Service user</b>	<b>Complainant (if different)</b>
C34/10		Concerns from complainant about information given from Dr to solicitors which were untrue.	Complaint ongoing.	WAA		
C35/10	21	Complaint about the services complainant's son received since leaving Honeybourne and events directly related to his need to be sectioned.	Improved communication between teams with respect of medicine management.	WAA		
C36/10		Experience in therapy group and being given an injection by male member of staff with another male staff present.	Apology offered. Explanation given re group work response.	SMS		
C37/10		Concerns about CRHT.	Meeting with family offered to explain service.	WAA		
C38/10	34	Access to health records	Complainant received copies of health records.	WAA		
C39/10		Communication issue.	Ongoing.	WAA		

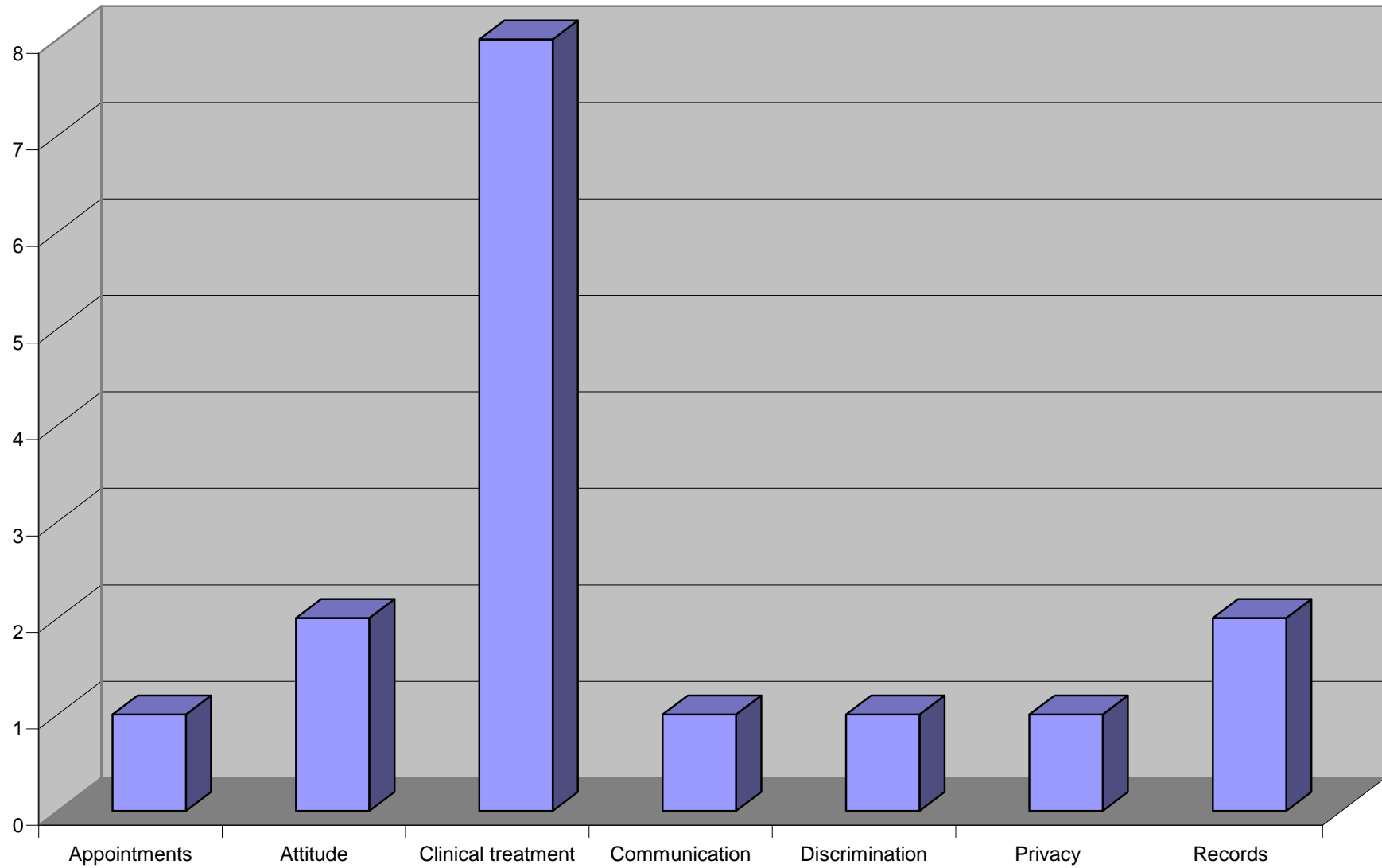
**Receipt date between  
1<sup>st</sup> April and 30<sup>th</sup> June  
(Outstanding from previous quarters)**

<i>Reference</i>	<i>Response time in working days</i>	<i>Complaint</i>	<i>Action taken</i>	<i>Strategic Service Unit</i>	<i>Service user</i>	<i>Complainant (if different)</i>
C15/10	92	A service user complained that, although she felt that the Crisis Team had listened to her, the PCAT Team had not done so.	Meeting with member of staff. Actions identified. Complainant happy with response.	WAA	White British	-
C17/10	60	The widow of a service user complained about delay in diagnosis of autism and personality disorder.	The Medical Director will meet with the complainant to discuss the outcome of the internal review.	WAA	White British	-
C18/10		A service user complained about various aspects of support received.	Local manager will attempt to resolve informally. Complaint resolved informally.	WAA	White British	
C19/10		A service user complained about the way in which a social worker had treated her.	The team manager will contact complainant and discuss how to proceed. Complaint resolved informally.	WAA	White British	
C20/10	59	The mother of a service user complained about the implementation of a new carer regime without consulting her and a lack of care.	The complaints manager will attend a meeting with the care provider and complainant.	WAA	Not stated	
C21/10		A service user complained about a lack of support.	Complaint resolved informally.	SMS	Not stated	
C23/10		A service user complained about lack of support.	Complaints manager and team manager met complainant. Team manager arranged an assessment with a different member of staff. ICAS was asked to contact complainant.	WAA	White British	

### Complaints by Strategic Service Unit (July – September 09)



### Complaint by Subject (KO41) (July – September 09)



	<b>Admissions</b>	<b>Appointments</b>	<b>Attitude</b>	<b>Clinical care</b>	<b>Communication</b>	<b>Decisions of Trust</b>	<b>Discrimination</b>	<b>Independent sector</b>	<b>Personal records</b>	<b>Privacy</b>	<b>Procedures not followed</b>
<b>Apr – June 08</b>	0	1 (7%)	1 (7%)	11 (73%)	0	0	0	0	0	0	2 (13%)
<b>July – Sep 08</b>	1 (8%)	1(8%)	2 (15%)	7 (54%)	1 (8%)	0	0	0	0	0	1 (8%)
<b>Oct – Dec 08</b>	0	2 (13%)	1 (7%)	8 (53%)	4 (27%)	0	0	0	0	0	0
<b>Jan – Mar 09</b>	0	0	0	3 (38%)	1 (13%)	2 (25%)	0	0	1 (13%)	0	1 (13%)
<b>Apr – June 09</b>	0	3 (13%)	1 (4%)	16(70%)	2 (9%)	0	0	1 (4%)	0	0	0
<b>July- Sept 09</b>	0	1 (6%)	2(12%)	8(50%)	1(6%)	0	1(6%)	0	2(12%)	1(6%)	0



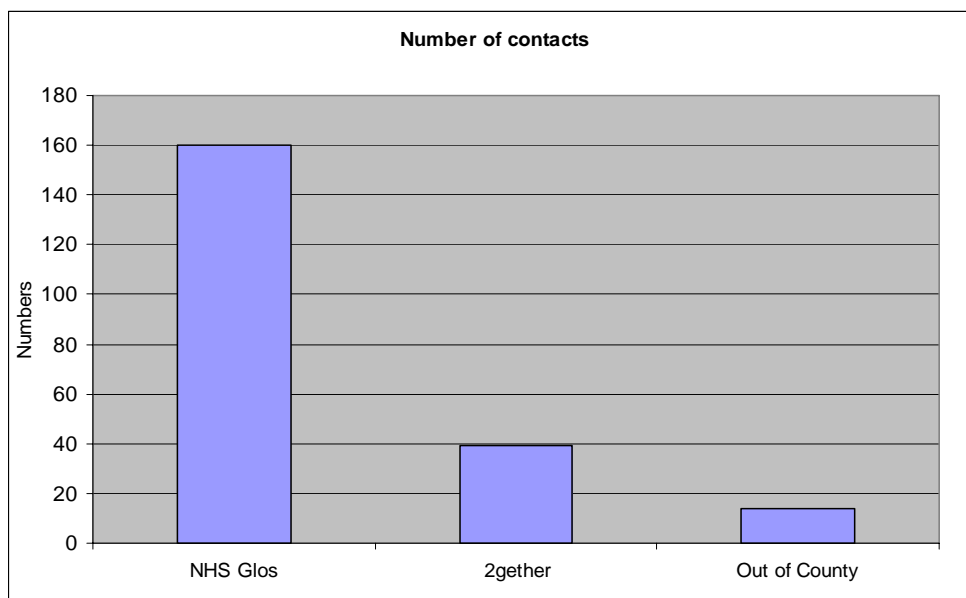
**GUIDE & PALS**  
**(Patient Advice and Liaison Service)**  
**Quarterly report for the 2gether NHS Foundation Trust**  
**Period 01/07/09 – 30/09/09**

### 1. Purpose

This report provides information of PALS activity within the period 01/07/09 to 30/09/09. It highlights to the Trust Board the issues being raised by users and carers who contact our service. There have been 213 contacts to PALS across Gloucestershire during the second quarter. There were 14 Out of Area contacts.

### 2. Contacts

The first graph shows the number of contacts to PALS across the county for the second quarter. There were 39 for the 2gether NHS Foundation Trust.



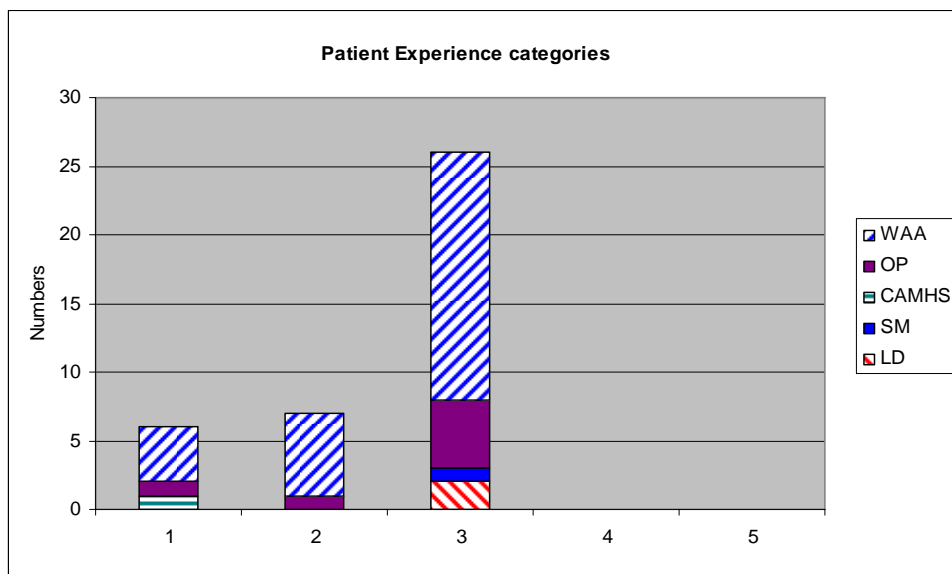
### 3. Numbers of contact by Care Group

<b>Working Age Adult</b>	<b>27</b>
<b>Older People</b>	<b>8</b>
<b>Child and Adolescent</b>	<b>1</b>
<b>Substance Misuse</b>	<b>1</b>
<b>Learning Disability</b>	<b>2</b>

### 4. Categorising the Patients Experience

The following graph shows the number of contacts that have been made within each Care Group, within the five main Patients Experience categories, which are:

1. Access and waiting
2. Safe, high quality co-ordinated care
3. Better information, communication and choice
4. Building relationships
5. Clean and comfortable place to be



The themes have been further broken down into sub categories, shown as charts.

### Patient Experience Category 1 Access and Waiting 6 contacts in this category

Sub category	No	Outcome
<b>Service not available:</b>		
Transport for client with Dementia	1	PALS booked, issue resolved
GP on holiday-no appt available.	1	PALS facilitated appt with GRIP
<b>Delayed:</b>		
Appt. with Psychologist	1	Waiting time to long, info re crisis and GP provided
Delayed CBT	1	PALS facilitated by chasing appointment
Reply from complaints (sheltered housing)	1	Support to client Referred to ICAS
Child with Autism – OT adaptations and education provision delayed	1	Advised - Complaint to PCT and GCC

### Highlighting gaps in service provision across Gloucestershire

Recurring themes:

- Delay in provision of Psychological therapy. People have waited so long for the improvement in appointments in this area and also heard about IAPT so are quick to expect things to improve.
- Delay in adaptations from OT services. This has been highlighted to GCC and NHS Gloucestershire, there is a long wait for OT services, resources are inadequate.
- Access to urgent mental health services through GP when practice appointments not available - further education within general practice necessary. This message was echoed by Carers in recent feedback from the MH Carer Coordinators.
- An issue being raised by carers is lack of mental health support to users of services. This theme concerns lack of day activities, since the closure of day care provision and the long wait for OT activities to replace them. It is encouraging that the Social Inclusion

agenda will be making this happen soon but it has been quite a wait and difficult for Users and Carers.

**Patient Experience Category 2 Safe, high quality, co-ordinated care**

*6 contacts in this area 1 abandoned*

<b>Sub category</b>	<b>No</b>	<b>Outcome</b>
Clinical: Contact from carer concerned re perceived lack of input to cared for by ACT	1	Case ongoing. Letter sent to Manager, meeting agreed
Contact from Carer. Unhappy with mental health services suggesting missed diagnosis	1	Letter of complaint facilitated – ongoing support by PALS
Client had not felt listened to for the past 22 years. CBT not always appropriate, 12 week Course at Burleigh House good	1	Wished to feed in comments re mental health care
Assessment for CHC, client with dementia, not yet done, Carer enquiring	1	Information provided, client empowered to speak to staff and request assessment
Referral between clinicians -wanted second opinion	1	Client feels Psychiatrist is pushing to discharge and does not appreciate how unwell he feels. Long discussion and guidance, felt empowered to speak to Psychiatrist
Concern expressed by User Participation worker re Medication distribution	1	GP, Pharmacy and Medicines Commissioning Team linked by PALS – issue resolved

**Outcome: Patient Experience Category 3 Information, communication and choice**

*26 contacts under this category*

<b>Sub category:</b>	<b>No</b>	
<b>Communication:</b> Inadequate -	2	Improved communication facilitated between client and MH team by PALS Advisor
<b>Advice provided:</b> Advocacy	3	Advice/Information provided and referral on to other sources of help if appropriate.  Listening and support also provided
Mental Health	3	
Dementia	3	
Records	1	
Complaints	2	
Carers issues	2	
Transport/DVLA	2	
Inadequate care	3	
Housing	1	

<b>Information provided:</b>		
Mental health	1	
Drugs and Alcohol	1	
Info in Bengali for person with PND	1	Translated information sourced
Communication with SHA	1	Client making comment re primary care mental health services

#### **Patient Experience Category 4**

There were no cases under this category this quarter.

#### **Patient Experience Category 5**

There were no cases under this category this quarter.

#### **Activities of the service during this quarter**

- **Change to Management**, there is now a Co-Management structure to GUIDe & PALS. The current manager has reduced her hours to 3 days a week has been joined by a co-manager who was previously the Project Manager for the introduction of the Information Bus and the Interpreting and Translation provision for NHS Gloucestershire.
- Collaborative planning continues for the introduction of the Information Bus. The working party consists of stakeholders e.g. GCC, Public Health, Cancer services and a representative from the LINK and two Village Agents. We hope for the delivery of the Bus in December /January, the building is underway at Torton Coach Builders.
- The Driver/Coordinator/Officer for the Bus has been appointed.
- From October 1<sup>st</sup> GUIDe & PALS will be the HUB for the 4 C's. **Compliments, Comments, Concerns and Complaints** are being invited from the public, to communicate on their experiences of the health services. This initiative has come out of the Listening, Responding and Improving document from the Department of Health 2008 regarding the management of complaints. Since the 1<sup>st</sup> of April 2009 complaints are now handled across Health and Social Care and there is more collaborative working to reduce the complexity of the process for the client.
- GUIDe & PALS are collaborating with the Palliative Care Group and will now be updating the Bereavement Directory for the county. The new Bereavement leaflet was produced this quarter.
- GUIDe & PALS are part of the membership of the Countywide Database group, ensuring consistency across Databases in the county. There is communication with GCC regarding the planning for an Information Hub as part of the Putting People First project, to ensure existing good databases are on board to be part of the future process.
- GUIDe & PALS are also members of the countywide Physical Disability Strategy Group with targets to disseminate information across the county particularly targeting older people and those with disabilities

## Promotion of GUIDE & PALS/The Key from July - September 2009

### Presentations:

- Talk at Great Western Court
- To County wide Arthritis group
- Drop in Centre in Stroud re: Learning Disability
- Talk to NATO staff coming to Innsworth (in Germany)
- Talk to Foxes Bridge Day Centre, Valley Road, Cinderford
- Christchurch

### Displays:

- Health & Wellbeing event, St Andrews Church, Cheltenham
- Arthritis Group
- Falls Prevention for SHA at Sanger House with Public Health
- The Shrubberies Roadshow – The Key
- The Milestones Roadshow – The Key
- Corporate Induction @ Sanger House monthly
- The Military & Civilian Services & Youth Tattoo @ Hardwick Court
- The Key - National Play Day @GL1
- Corporate Induction @ Dowty's - focus on the 4 C's and complaints
- NATO troops in Germany
- 2gether AGM @ The Guildhall
- 'Full of Life' @ Glos Rugby Club

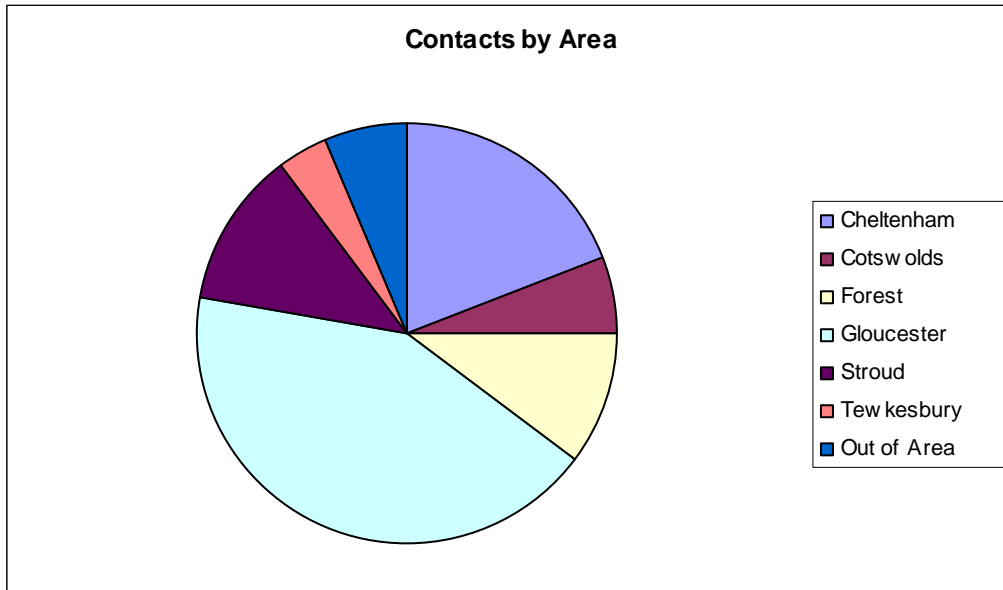
### Attendance:

- On the Sofa and Patients experience testimonials (Social Inclusion Agenda)
- Meeting with Mental Health Carer Coordinators quarterly
- Service experience report meeting
- User and Carer Best Practice meeting
- Attendance at User groups with User Participation worker

## GUIDE Report for the 2nd Quarter of 2009-10

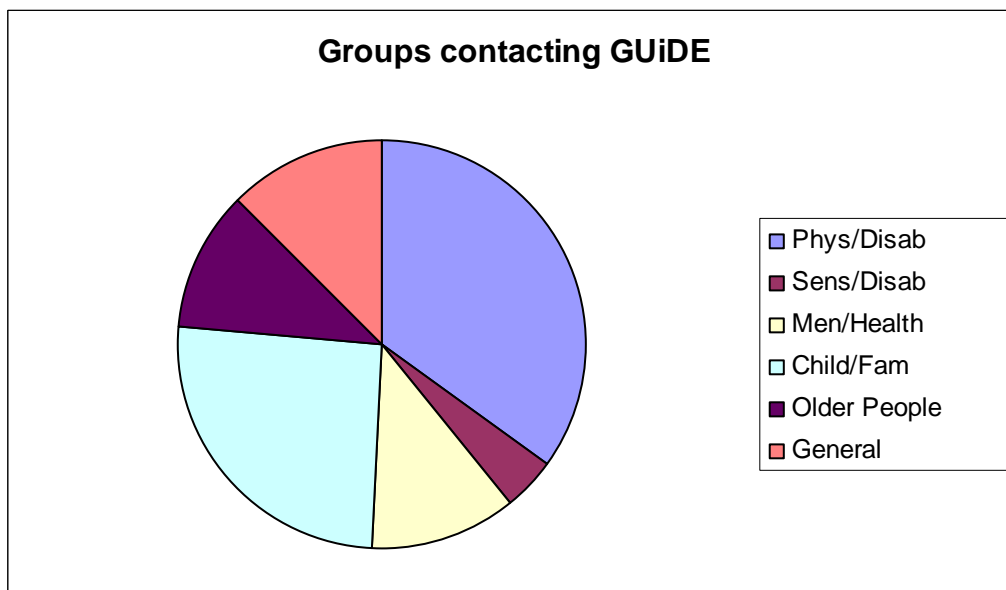
The purpose of the report is to reflect the contacts to and the activity within the service for the second quarter. There were 849 contacts to GUIDE and 213 to PALS. The numbers for Guide make up the charts in this part of the report. 93% of the calls were dealt with immediately or within 24 hours.

1. The first graph reflects the contacts across the area of Gloucestershire



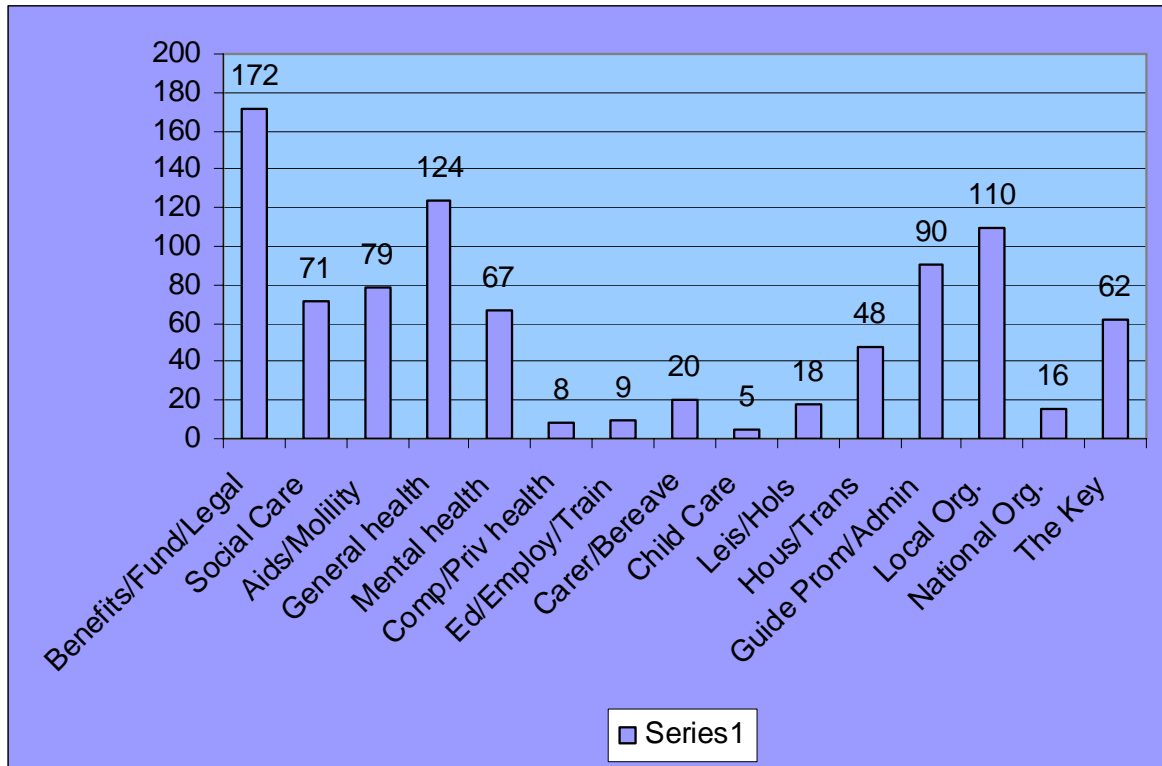
With the introduction of the Information Bus to visit areas of the county from January 2010 we hope for a more equitable distribution of contacts to the service

2. The second graph is the grouping of people who contact the service.

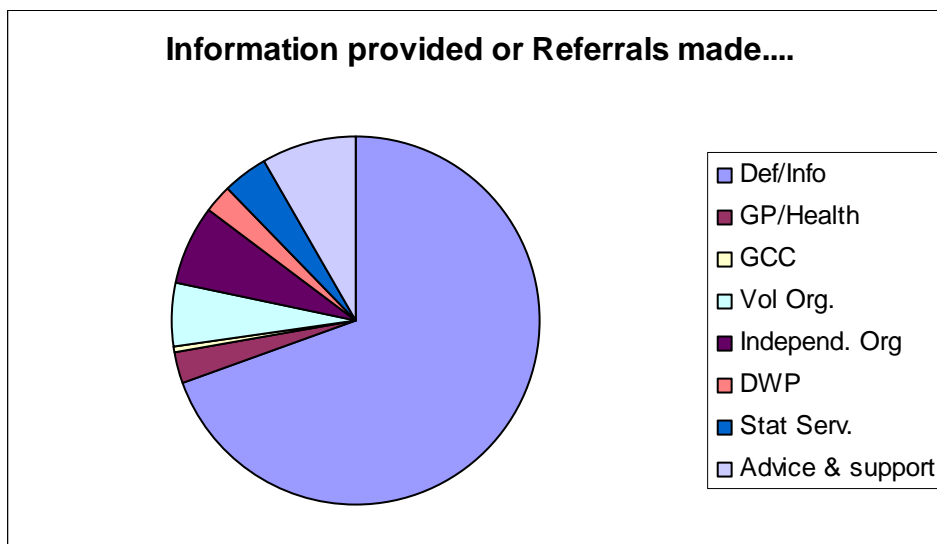


The largest group to contact Guide continues to be those with Physical Disabilities.

3. The third chart reflects the issues raised by and information provided to the contacts to the service



4. The final chart gives information about whether people have received definitive information from the service and those that have been referred on for further information





OLDER PEOPLE'S CATCH UP AND HAVE YOUR SAY SUMMARY JUL-SEP 09

Date and Venue		Comments	Action
5 July 09	Charlton Lane Cheltenham 5 carers	<p><b>Education Group Sessions</b></p> <p><u>What is dementia?</u> Very clear, it didn't feel rushed. It was delivered sensitively and we didn't feel just talked at but spoken to.</p> <p><u>How to manage behaviour</u> Information on communication was very helpful thinking about the different ways to respond. Something more practical might have helped – more personal to our own problems.</p> <p><u>What help is available – Alzheimer's society</u> Interesting literature and booklets. Having handouts is helpful. Have since attended the memory Café – found it very friendly and helpful.</p> <p>'I don't recall coming away from any session thinking it was a waste of time'</p> <p>'Meeting other people – gives you permission to respond normally to others.'</p> <p>'I wonder if you could have coffee, tea in the middle'</p> <p><u>Services</u></p> <p>3 out of 5 carers have had a carer's assessment. Carers talked about how they had accessed the carers' education group</p> <p>Training for the carer should be offered when the person is first diagnosed – its important to know if you are doing the right thing and to know what help is available.</p> <p>One carer felt the education group was pitched at exactly the right time values contact with MH nurse who keeps a close watch – he doesn't know how other people manage – having someone to contact gives you a sense of security.</p>	<p>Feedback to carer education steering group</p> <p>Feedback to Alzheimer's Society</p> <p>Will aim to negotiate breaks at the beginning of each group as need of groups vary</p> <p>Feedback for Memory Assessment Service.</p> <p>Carer Involvement Leaflet and</p>

		<p>Finding out about the carers group should be part of the routine – not left to chance – one carer only found out about the groups through social services rather than through 2gether.</p> <p>Having to pay for day care is wrong – this should be part of treatment.</p> <p>‘There seems to be a lot of duplication – surgery nurse visits suggests you need a bath chair then they contact social services they send someone who say a walking frame might help then it’s the physiotherapist they arrive and then say it might be helpful to have something by the back door then the occupational therapist comes out.’ Not everyone seems to have access to the same information.</p>	<p>Education Group Leaflets should be offered routinely to carers.</p> <p>Feedback back to PCT re joined up services</p>
4 Aug 09	<p>Colliers Court</p> <p>2 carers</p>	<p>Carers present felt it would be helpful for CUAHYS to follow directly on from the six week group without a break.</p> <p><b>Education Group Sessions</b></p> <p><u>Everyday Activities</u>  Good leaflet about eating  Really made you think about ensuring that you don’t take over when tasks are difficult but find ways to help the person to stay as independent as possible.</p> <p><u>What help is available</u>  Surprised at the number of services available  Viv was very good  Gave you the confidence to make a one to one appointment with Viv which is a really good service.  Overall felt the course was very good helped you to understand the illness more</p> <p><u>Services</u>  It was the GP that first picked up the problem when the person was visiting about a physical problem. The GP then contacted the spouse. Carer is happy with service provided thus far. However the situation remains difficult as the person with dementia won’t accept treatment which is very frustrating for the family.</p> <p>Having recently moved into the area the cared for had been visiting the GP for a couple of years and was treated for depression – a family member felt it was more</p>	<p>Agreed to trial this for the next group of sessions</p> <p>This was a new session so good to have positive feedback</p> <p>Feedback to Alzheimer’s Society</p> <p>Important to be positive in support for family members when the person with dementia won’t accept help – important to consider Best Interests</p>

		than this and wrote to the GP outlining symptoms. Following this the person was referred to Colliers Court.	
20 Aug 09	Holly House 4 carers	<p><b>Education Group Sessions</b></p> <p>Overall people were glad they came to the groups – <i>‘to be honest I didn’t want to come but I am glad I did – I am now more understanding and think what it must be like for Mum’</i></p> <p>Expenses, venue, facilitators all good Would recommend to others.</p> <p><u>Catch Up groups</u></p> <p>Carers felt it would be better to do it while it is fresh in the mind so follow on directly from programme. Newsletter about services would be good – informed about Alz Soc, Carers Glos and 2gether trust newsletter and how to sign up to receive.</p> <p><u>Services</u></p> <p>GP – 2gether (Consultant) brain scan follow up with the consultant referred to this group but not ongoing support – if things go wrong then back to the GP. Would be nice to have someone every now and again checking back to see if things are Ok – you wouldn’t feel so alone with it then.</p> <p>For carers who get a break Manor Day is wonderful</p>	<p>Discuss at Carer Education Steering Group and catch up facilitators.</p> <p>Managing Memory Service, Alzheimer’s Society and new ways of working i.e. Dementia Care Advisors should help with this.</p>
04 Sep 09	Cheltenham 5 carers	<p><b>Education Group Sessions</b></p> <ul style="list-style-type: none"> <li>• Being able to talk in a group</li> <li>• The two leads were excellent – so welcoming – explained things really well – really grateful for their help and support.</li> <li>• Felt all the sessions were really useful</li> <li>• Carers felt having separate groups for carers who are partners/husbands of the person with dementia and other family members (sons. Daughters, siblings) would be better as their experiences are different.</li> </ul> <p><u>Services</u></p> <p>Carers register – asked to complete form at Doctor’s surgery – but what does it mean – you complete it hand it in and hear no more – What is the point?</p>	<p>Given current resources and numbers wishing to attend groups it is difficult to organise groups in this way – however this feedback is important and will be considered in planning future groups.</p> <p>Advised what is supposed to happen. Will feed this back to the carers lead for PCT who is currently working to improve</p>

		<p>At one time I had no information and didn't know where to go then my wife was admitted into hospital and when she was discharged I was getting information all the time and I didn't really know who was sending it – forms to complete different people visiting and although it helped I needed someone to explain what was going on and what I could expect in the future. When the community nurse came that was good because she sat down and explained it – that's what you need not loads and loads of paper and different people.</p> <p>Diagnosis – carer experiences</p> <ol style="list-style-type: none"> <li>1. Referred by GP to Charlton Lane saw the consultant was given the diagnosis and then offered 12 month follow up – we didn't know what to expect and got no information. I got worried as husband was getting worse and asked for an appointment and we did see the consultant again but I didn't find it very helpful and had to ask if there was anything that would help me as a carer.</li> <li>2. GP referred straight away – consultant was really helpful – set in motion contact with social services for help and told us about Crossroads – who are excellent. I was reluctant to use Crossroads but I can't speak to highly they are really good with my husband and he enjoys the time he spends with them.</li> <li>3. Referred by GP and we now have a community nurse – having someone visit really helps although sometimes I wish I could talk to the Community Nurse alone – the same with the consultant – you don't want to keep contradicting the person you care for when they are talking.</li> </ol>	<p>practice in GP surgeries</p> <p>This demonstrates the value of face to face contact and individual explanations. Important considerations for Memory Assessment services. Managing Memory Together, Dementia Care Advisors (when we have them) Alzheimer's Society and Carers Gloucestershire can all support this process.</p> <p>Useful feedback that will contribute to 'pathways' in the new memory assessment service</p> <p>The CPN advised that family members are free to contact the nurse or consultant at any time and if required appointments can be made to see the carer alone. Carers felt they needed to be made aware of this because you tend to think you can't and that you are asking too much. It would be good if it was built into the appointment time.</p>
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<p>07Sep 09</p>	<p>Cirencester 5 carers</p>	<p><b>Education Group Sessions</b>  Behaviours that challenge -  Although good the session was too general. It would have been useful to have looked at different scenarios and how to deal with them – perhaps if each of us had been asked to identify a problem and then looked at solutions or ways to deal with them.</p> <p>Everyday Activities – OT -  Use of powerpoint was not good – there was too much text and not enough interaction with the audience.</p> <p>Overall found the sessions very helpful. Good to meet other carers – helps you to feel less isolated. Good to have a refreshment break and biscuits.</p> <p><u>Environment</u></p> <ul style="list-style-type: none"> <li>• Room acoustically not good due to height of ceiling</li> <li>• Not private enough and sometimes noisy (people talking in the background)</li> <li>• Volume of traffic – doorbell going, people walking by</li> <li>• If using PowerPoint make sure the equipment works beforehand</li> <li>• Small room used for the relaxation session was much better</li> </ul> <p><u>Services</u></p> <p>Knowing what to expect from a service is important eg. What to do if you need incontinence pads – carers had different experience.</p> <p><u>Diagnosis</u></p> <ol style="list-style-type: none"> <li>1. Spoke with GP referred to nurse in the practice who then referred us to CMHT everything visit was followed up by a letter that was copied to me as the carer – so I was kept informed – even the letter from the DVLA was copied to us. (St Peter's Rd) The surgery also told us about the carer education groups. We think it has been very good.</li> <li>2. GP referred straight away we saw consultant who diagnosed vascular dementia. We were told there was no treatment for this type of dementia and that we would</li> </ol>	<p>Feedback to facilitator</p> <p>Facilitator aware of problems and this has now been addressed</p> <p>When groups are large alternative accommodation is a problem. Group organiser is aware of problems and will seek to minimise difficulties.</p> <p>KH agreed to find out if there was a specific procedure</p> <p>Useful feedback for Memory Assessment Services</p> <p>KH explained process and promised to follow up with care coordinator.</p>
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	<p>be reviewed annually. We did have an assessment with Nina and she told us about the education group. My wife's condition has changed and we need to see someone again.</p> <p>3. GP – referred to consultant everything fine although not enough information. Contacted the Alzheimer's Society who was excellent and took us through the process – put us in touch with Carers Gloucestershire and explained what was available to help us.</p> <p>Respite Care – how do you get it? Dad is exhausted because Mum keeps him awake at night – he needs someone to stay overnight sometimes.</p> <p>Trying to get a break is difficult everywhere you contact has waiting lists</p> <p>Too many assessments – should be joint health and social care – not one then another asking the same questions</p> <p>Support needed for carers in dealing with stress – although sessions very good need more ongoing support.</p>	<p>Feedback for PCT and GCC</p> <p>Feedback for PCT</p> <p>Advised about Looking after Me courses</p>
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**Patient Experience Report  
Health Facilitation Team  
Learning Disability Services  
Quarterly Report July to September 2009**

**Purpose**

This report provides information of Health Facilitation Team activity within the period 01.07.09 to 30.09.09. It highlights to the Trust Board some of the issues being raised by care providers, users and carers who contact our service. There has been a notable increase in contacts from care home providers with the annual health checks from GP practices and service users accessing acute hospitals with concerns relating to wards not communicating with care providers when planning discharge, reading the Traffic Light Hospital Assessment or making 'reasonable adjustments'.

**Examples:**

**Scenario:** Concern from a home manager and team members from one of the CLDT's, who were concerned about admission of a client to GRH when experiencing difficulty in swallowing, where the best interest process and DNAR was felt not to have been followed appropriately. Client died

**Contact:** Concern

**Details:** Emergency Hospital Admission

**Action:** Advised CLDT staff to write report of patients' journey, contact LD community Services Manager and advise the home to make a formal complaint. Information on who to write to provided from Hospitals Trust and PCT complaints departments.

**Outcome:** Investigation carried out by Hospitals Trust. HFT held with CLDT staff. Further questions on investigation report and coroners report, ('diagnostic overshadowing') DNAR status to be clarified. Aim is to have a learning outcome and closure for both care home and CLDT staff. To inform Medical Director of Hospitals Trust and together trust of final outcome. Ongoing.

**Scenario:** Best Interests meeting initiated by a CLDT physiotherapist. Client with autistic spectrum disorder to be admitted for a right hip replacement. Client said to have other health needs and refusing to have treatment,

**Contact:** Concern

**Outcome:** As unable to attend best interest meeting, advised physiotherapist on options, to take forward to the BI meeting. 1. Plan pathway, before during and after admission, involve ward sister and GP practice, 2. Involve LD Liaison Nurse to assist with process (admission planned in Feb 2010), 3. Involve CHC nurse, in view of changing needs. 4. Plan second BI meeting nearer admission. Identify co-ordinator and clarify each stage of admission process. 5. Decide on pre admission visits to reduce anxiety and fear. 6. Provide accessible information prior and during admission. 7. Work with care home to plan access to hospital for carers (trust clinical policy on staff supporting vulnerable patients) 8. Is placement going to be appropriate on discharge. To be kept informed of progress. Ongoing.

**Scenario:** Concern from a home who indicated that their local GP surgery had refused to undertake annual health checks for their LD service users.

**Contact:** Concern

**Outcome:** Liaised with Clinical Change Commissioner for LD, as 12 homes had not signed SLA with PCT. Discussion with senior partner of practice. Practice felt they were meeting LD clients' ongoing health care needs. Stated CLDT's are specialist workers and service and should be completing annual health checks.

Visit to home. Advised to continue completing "My Health Assessments" as part of the HAP and request health assessments from GP practice, to be placed in service users' personal folder.

Advised to consider either changing GP practices or approaching another GP practice who has signed the SLA and do the check, then take the completed annual health checks back to their main practice. Home to keep me informed.

**Scenario:** Parent/carer liaised with the HFT, about daughters' initial pre-admission to CGH prior to a hospital admission.

**Contact:** Advice

**Outcome:** Visit to see parents and daughter. CLDT not involved.

Advised to complete Traffic Light Hospital Assessment. Colour pictorial booklet of hospital and ward given to family. Information provided on Hospital PALS, Carers info (car parking, badges, ward responsibility i.e. 'reasonable adjustment' Advised on LD Hospital Liaison Nurses role to contact for support in Jan 2010. Ongoing

**Scenario:** Concern from a CLDT Physiotherapist about an LD patient who she initially assessed, would benefit from a different walking frame and a review of her mobility at home .Referral made to a Community Hospital Physio. Lead physio declined to see LD patient and referred back to CLDT physio, saying they had experienced LD patients being noisy and disruptive in the past. Agreed to see LD patient once.

**Contact:** Advice

**Outcome:** Discussion with CLDT Physio. Suggested liaising with the physio department and hospital matron/manager, to set up some training, identify their concerns, in LD awareness, basic communication and 'reasonable adjustment'. Awaiting outcome.

**Scenario:** A visit to a care home and seeing two care managers from and LD unit and CLDT unit, were not aware of HAP's and traffic light hospital assessments, which could be offered to their service users, when admitted to CGH or GRH.

**Contact:** Advice and Information

**Outcome:** Outlined issues around health inequality. Provided packs on HAP, CD ROM, Traffic Light Hospital Assessments and resources.

Traffic Light Hospital Assessment forms now to be used for all admissions to the acute and community hospitals.

## **Summary of visits and training:**

- 10 group homes, HAP (Health Action Planning) training in LD awareness, Traffic Light Hospital Assessment with info and resources, packs and CD's
- 4 AOC's (Adult Opportunity Centres) with support workers and clients
- 4 parent/carers, Brandon Trust 'peer group' managers,
- 2 GCC 'Fastrack' Groups (staff and clients), and
- 1 GCC Healthy Living group.
- 3 wards at GRH, Presentations and resources on LD
- 3 county LD private organisations and 3 county conferences (Social Inclusion, Diabetic Retinopathy Clinics, Assoc of Dental Nurses).
- Primary Health Care - 5 GP's requested advice on annual health checks and HAP's.
- 1 GP surgery advice on HAP, access to services.
- 3 displays at AGM's – 2gether trust, PCT and Carers Gloucestershire

## **Health Action Planning Packs (including easy read guide and CD)**

- Ongoing care home visits to support and advise on annual health checks and HAP's. Data base being set up to measure these outcomes.
- HAP's available on Intranet and internet for all Trust staff and care providers to access.

## **Traffic Lights Hospital Assessment**

- Assistant Director of Nursing in the hospitals Trust will be making this document available in the pre-assessment clinics for planned admissions and the availability of the document in the emergency departments so that staff can have them ready for a parent/carer to complete in the case of a patient with a learning disability being admitted as an emergency, if they have not completed these prior to admission.
- Continuing to be promoted across the county across LD services, WAA Leads, Older people service Leads, supported accom i.e. Brandon Trust, Orchard Trust, Comm Care Ltd, Parallel Options, Carers Gloucestershire, parent/carers and trust website.

## **Leaflets and Booklets**

- Going into Hospital leaflet. Now printed and available and to be made available on acute hospital wards and A& E in both hospitals. To be made available in LD inpatient units, all community and MH hospitals.
- The Hospital Communication Book – version 2. Distributed to all wards by the PPI dept in CGH and GRH. To be given to Link Nurses/Workers when training programme commences as part of their resource pack.
- CLDT Leaflet. To be taken back to the new LD Communications and Information Committee for discussion and signing off.
- Maternity Communication booklet and leaflets for PCT now printed.

## **HAG (Health Action Group)**

- The LD Learning Disability Board has drawn up a Health Plan for 2009 to 2011, from 'The Big Health Plan' (from Valuing People Now and Healthcare for All). 12 health targets have been identified. Six targets will be looked at within the next 12 months by the HAG.
  1. Annual Health Checks
  2. Liaison Nurses at Hospitals
  3. Easy to Understand Information
  4. Training for Health Services
  5. HAP's (Health Action Plans)

## 6. Identification of people on a register

### **Learning Disability Hospital Liaison Nurses**

- Two LD Hospital Liaison Nurses will be starting their induction on 16.11.09, and will be based at Riverside House CGH. Both posts will be monitored and reviewed by the LD Hospital Liaison Nurse Steering Group.

### **A journey through inpatient services – DVD and photographic booklet**

- Following the launch in July 2009, DVD's and the photographic booklets have been distributed to both Hollybrook and Westridge inpatient units. They have also been made accessible on the trust internet web page, so they can be viewed and downloaded with subtitles, and /or sign language.
- DVD's are being distributed to parent/carers and service users. This is being monitored by both inpatient units, with feedback to the HFT.
- Two parent/carers have found the DVD and photographic excellent, easy to follow, understanding the journey and intervention offered.

### **Ongoing projects**

- Primary Health Care – Clinical Change Commissioner for LD visiting GP surgeries, over next three months, following up annual health checks and 'reasonably adjusted' access to health services. Having identified concerns HFT will then follow this through and provide advice and support on HAP's, education and training, LD information and resources. This will be recorded on our data base.
- Meetings in progress with the Hospitals Trust Education and Training dept, to develop an LD e.learning programme and 'Making it Happen' conference for present and potential link nurses/workers on each ward.
- Palliative care – resource pack being collated.
- Carer's information pack to be reviewed in partnership with MENCAP, Carers Gloucestershire and Social Services.
- Health Facilitation Resource LD folder being collated. This will be accessible on our trust website, intranet and distributed to CLDT teams, inpatient units, link nurses, community and MH hospitals.
- Record of LD admissions to acute hospitals – Awaiting confirmation fro LD Governance Committee to implement this project. Database to be set up, to record LD admissions from all CLDT teams and supported accommodation. Aim to build up evidence on positive practice, concerns, waiting times, parking issues and outcomes. To be taken back to the divisional leads and LD teams. Aim to measure this against standards and set up protocols of practice as well as training needs, when working with patients with an LD.
- 2<sup>nd</sup> audit to record all HAP plans from inpatient units. This will also be built into the inpatient unit pathways.
- Learning Disability, Health Facilitation Team internet and website link and being updated, outlining functions and downloadable resources. Links to other local and national websites and easy read sites.
- Health Facilitation Team LD Library being re-catalogued. Resources can be viewed on our HFT intranet page.
- Health Facilitation Team developing an interactive, accessible and easy read website. Funding being sought in two phases through the LDDF (Learning Disability Development Fund).

Health Facilitator, Learning Disability Services.

